

**IZABELA NOWAK, PIOTR ŚWITAJ, KATARZYNA CHARZYŃSKA,
MARTA ANCZEWSKA**

SOCIAL INCLUSION THROUGH INTERVENTIONS TARGETING PSYCHOSOCIAL DIFFICULTIES IN SCHIZOPHRENIA

Abstract

Personal recovery has three main dimensions: hope, agency and opportunity. The opportunity links it with social inclusion and thus peoples' participation in a wider society. Schizophrenia as a complex mental health disorder is ranked among the leading causes of disability worldwide. It influences all major areas of life: emotional and cognitive functions, relationships with others, employment and social activities participation. This paper addresses some of the crucial social challenges faced by schizophrenia sufferers and provides examples of interventions aiming to counteract their social exclusion.

Introduction

Social inclusion is defined as a consequence of a complex interactions between personal and environmental characteristics, which enhances a person's opportunities in gaining access to community-based resources and activities, performing valued and expected social roles relevant to age, gender and culture; being appreciated as a competent individual who is trusted as to social roles performance and belonging to a social networks which are the source of mutual support (Cobigo et al., 2012).

Traditional measures of social inclusion used to be related to financial well-being, consumption and income acquisition which consequently lead to solutions focused on addressing employment issues (Cobigo et al., 2012). Although, the relevance of these factors is unquestionable, the psychological well-being and social connectedness should be taken into consideration (Craig et al., 2007; Sherwin, 2010). Personal change, empowerment, social reengagement and creation of accepting social environments are important aspects of recovery from schizophrenia (Tew et al., 2011; Warner, 2009).

Contemporary psychosocial approach focuses on psychological and contextual factors guiding progression beyond the psychological effects of schizophrenia towards an illness acceptance, service users' strengths, shared decision-making and social inclusion (Bevan et al., 2013; Slade, 2009). It may also refer to the societal perspective of psychosocial difficulties such as formal and informal organizations which provide services related to community activities, work environment, government agencies, communication, legislation or attitudes and ideologies (WHO, 2001b).

In recent years there has been growing interest in the idea of recovery from mental illness, not in the sense of clinical cure but rather in terms of being able to lead a meaningful and satisfying life, despite symptoms and problems (Bevan et al., 2013). Personal recovery has three main dimensions: hope, agency and opportunity. The opportunity links recovery with social inclusion and thus peoples' participation in a wider society.

Schizophrenia is a complex mental health disorder which is ranked among the leading causes of disability worldwide (Prince et al., 2007). Although various degrees of recovery from schizophrenia are possible (Harrow et al, 2005), many of those affected suffer from a substantial decline in their functioning and ability to reach their full potential. An international study using data from 37 countries found that over three quarters of patients with schizophrenia did not achieve functional remission and less than a quarter were in paid employment (Haro et al., 2011). Important challenges on the way to recovery from schizophrenia are stigma and discrimination (Brohan et. al., 2010; Thornicroft et al., 2009) as well as lack of social policies addressing the needs of service users in the workplace and in the society (WHO, 2001b).

The aim of this article is to share with academics and mental health providers some ideas regarding major environmental barriers to social inclusion of people diagnosed with schizophrenia and psychosocial interventions targeting these barriers.

Psychosocial difficulties in schizophrenia and their conceptualization

The WHO's International Classification of Functioning, Disability and Health (ICF), based on a biopsychosocial approach, indicates that a person's functioning depends on the interaction between health conditions and contextual factors (personal and environmental) and is not necessarily a direct consequence of health problems (WHO, 2001a). Living with schizophrenia goes beyond the presence of psychopathological symptoms and involves difficulties related to biological, psychological and environmental factors (Broome et al., 2005). The most frequent psychosocial difficulties in schizophrenia are related to the areas of psychopathology, overall disability and functioning, relationships with others, cognitive functions, emotional functions, quality of life and wellbeing, employment, and energy and drive (Świtaj et al., 2012).

Community-based services provision

Modern mental health policies promote community-based services, which foster person-centred, recovery-focused care, thus contributing to social inclusion of people with schizophrenia (Cobigo & Stuart, 2010). Services user-run, self-help or mutual support activities are based on a more democratic and less hierarchical approach than traditional services (Brown et al., 2008). Drop-in centres, residential programs, outreach services or vocational programmes run by paid staff with mental health disorders provide an opportunity for helping oneself and others through recognizing one's own potential to help others or through gaining inspiration from role models (Linhorst, 2006). Good practices of mobilizing the power in relationships with others are implemented in the Hearing Voices Network, where voice-hearers support each other by sharing ideas for understanding and managing of their voices (Tew et al., 2011). Rethink (www.rethink.org) is the largest severe mental illness charity for users, carers and professionals or volunteers working in the mental health field. It provides a wide range of community services including employment projects, supported housing, day services, help lines, residential care, and respite centres. Social enterprise model recognizing the importance of

sustainable supportive communities construction which develop their own businesses and infrastructure is an alternative approach (Mandiberg, 2012).

Stigma and discrimination

People with mental health problems experience discrimination in terms of initiating and maintaining friendships, intimate relationships, employment or housing possibilities (Thornicroft et al., 2009). The internalization of stigma negatively affects hope and self-esteem (Yanos et al., 2008), self-efficacy (Kleim et al., 2008), social adjustment (Perlick et al., 2001) and psychological and subjective well-being (Magallares et al., 2013).

The GAMIAN-Europe study run among service users with a diagnosis of schizophrenia or other psychotic disorder across 14 European countries (Brohan et al., 2010) points out that 41.7% of respondents reported moderate or high levels of self-stigma, while 69.4% – moderate or high perceived discrimination. Negative attitudes towards persons with mental illnesses which are held not only by the general public, but also by employers and healthcare professionals may undermine people's sense of competence (Cobigo & Stuart, 2010; Hughes et al., 2009; Marwaha et al., 2007).

It has been suggested that mass anti-stigma interventions targeting the general public may disrupt the vicious cycle of negative feedback caused by public stigma, consequently reducing self-stigma among people with mental health problems (Evans-Lacko et al., 2012).

“Open the Doors” program uses social marketing techniques to raise awareness about mental health problems (Warner, 2005), aims to decrease the need within the social mainstream to keep social distance from people with mental health problems (Tew et al., 2011).

“Like Minds, Like Mine” (<http://www.likeminds.govt.nz/>) develops its anti-stigma messages by working with consumers and family members and listening to their views.

“StigmaBusters” fights the inaccurate, hurtful representations of mental illness, breaks down the barriers of ignorance, prejudice, or unfair discrimination by promoting education, understanding and respect.

“In Our Own Voice: Living with Mental Illness” (www.nami.org/template.cfm?section=In_Our_Own_Voice) offers video and presentation materials which can be used by trained consumers and families to present on mental illness in their communities.

Housing

Safe and reasonably priced housing is crucial for people with mental health problems (Linhorst, 2006). It may improve their level of social functioning, care satisfaction (Fakhoury et al., 2002) and quality of life (Nelson et al., 2006). The unavailability of low-cost accommodation and landlords' unwillingness to rent it to people with mental health problems is the main barrier to independent living, which is more socially including than living in residential settings (Linhorst, 2006; De Heer-Wunderink et al., 2012).

Supported housing – a stable accommodation with mental health professionals' assistance is an empowering intervention where people have influence over their place of residence and have a control over the way of living in this place. Living with family members or psychiatric group homes have been rated as least empowering, probably due to perceived control (Chilvers et al., 2006; Linhorst, 2006).

Employment and work environment

Work plays an important role in the process of recovery (Shepherd et al., 2008), improves clinical condition and diminishes emotional discomfort (Bell et al., 1996), mitigates sense of purposelessness and feeling of alienation. Employment promotes financial independence, subjective sense of empowerment and integration into the community (Linhorst, 2006). People diagnosed with schizophrenia are much less likely to be employed compared to the general population (Haro et al., 2011). Self-employment, social enterprises, sheltered workshops or volunteer work are the on-hand labour market solutions.

Supported-employment programs are interventions useful in finding competitive employment and working more hours (Bond et al., 2012), however long-term outcomes suggest that in many cases it does not result in full employment and financial independence (Dixon et al., 2010) due to: clinical problems, disability policies, local economy, governmental and labour law regulations or stigma and discrimination (Bond & Drake, 2008; Rosenheck et al., 2006). Frequently supported-employment programs require health insurance coverage (Harvey et al., 2012).

The governments of the Organization for Economic Cooperation and Development member countries have implemented a variety of labour market initiatives to diminish unemployment rate among people with disabilities: changes in legislation, benefits for employees and return-to-work planning. The impact of these initiatives is not noticed due to the low awareness and low take-up (Clayton et al., 2011).

Welfare system and legislation

An inadequate benefit and welfare system may create significant barriers to employment and social inclusion (Bevan et al., 2013). Various policy and legislation initiatives are undertaken in order to remove these barriers.

The Universal Credit (UC) will enable people with disabilities to work part time and not to lose the majority of their benefits (Department for Work and Pensions, 2013). It is hoped that people with schizophrenia who start receiving social security disability benefits will remain on them permanently (Goldman, 2010), despite being employed. The Affordable Care Act passed in 2010 in the United States gives people with schizophrenia access to health insurance either through work or by qualifying for a range of public and private plans, which were not available before (Goldman et al., 2013).

Conclusions

The protection and treatment of people with mental disorders became a fundamental human right (UN, 1991) recognizing the need of life free from prejudices, protection from social exclusion and the right to receive best available treatments. The WHO Global Mental Health Action Plan (2013) goes even further, highlighting the need of applying evidence-based therapies and empowerment paradigm.

This paper illustrates the environmental factors that limit social inclusion of people with schizophrenia and provides examples of interventions aiming to counteract social exclusion. Societal barriers: inconsistent mental health policy practice, lack of access to mental health services, shortage of well trained professionals (Becker et al., 2013), lack of coordinated care programs, together with an inappropriate welfare benefits system proved to contribute enormously to the presence of psychosocial difficulties. Interventions targeting these difficulties revolve around increasing access to services, skills acquisition and integration enhancement.

Acknowledgements

The paper is worked out within the scope of the EU funded project MARATONE – Mental Health Training through Research Network in Europe. The project has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 316795.

References

- Becker, A. E. & Kleinman, A. (2013): Mental health and the global agenda. *New England Journal of Medicine*, 369(1), 66-73.
- Bell, M. D., Lysaker, P. H. & Milstein, R. M. (1996): Clinical benefits of paid work activity in schizophrenia. *Schizophrenia Bulletin*, 22(1), 51-67.
- Bevan, S., Gulliford, J., Steadman, K., Taskila, T., Thomas, R., Moise, A. (2013): *Working with schizophrenia: pathways to employment, recovery & inclusion*. Available from: <http://www.theworkfoundation.com/Reports/330/Working-with-Schizophrenia-Pathways-to-employment-recovery-andinclusion>.
- Bond, G. R. & Drake, R. E. (2008): Predictors of competitive employment among patients with schizophrenia. *Current Opinion Psychiatry*, 21(4), 362-369.
- Bond, G. R., Drake, R. E., Becker, D. R. (2012): Generalizability of the individual placement and support (IPS) model of supported employment outside the US. *World Psychiatry*, 11, 32-39.
- Brohan, E., Elgie, R., Sartorius, N., Thornicroft, G. (2010): Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: the GAMIAN-Europe study. *Schizophrenia Research*, 122(1-3), 232-238.
- Broome, M. R., Woolley, J. B., Tabraham, P., Johns, L. C., Bramon, E., Murray, G. K., Bramona, E., Graham, K. M., Pariente, C., McGuire, P. K., Murray, R. M. (2005): What causes the onset of psychosis? *Schizophrenia Research*, 79(1), 23-34.
- Brown, L., Shepherd, M., Merkle, E., Wituk, S., Meissen, G. (2008): Understanding how participating in a consumer-run organisation relates to recovery. *American Journal of Community Psychology*, 42, 167-178.

- Chilvers, R., Macdonald, G. M., Hayes, A. A. (2006): Supported housing for people with severe mental disorders. *Cochrane Database Systematic Review*, 4.
- Clayton, S., Bamba, C., Gosling, R., Povall, S., Misso, K., Whitehead, M. (2011): Assembling the evidence jigsaw: insights from a systematic review of UK studies of individual-focused return to work initiatives for disabled and long-term ill people. *BMC Public Health*, 11, 170.
- Cobigo, V. & Stuart, H. (2010): Social inclusion and mental health. *Current Opinion in Psychiatry*, 23(5), 453-457.
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., Martin, L. (2012): Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2).
- Craig, M., Burns, T., Fitzpatrick, R., Pinfold, V., Priebe, S. (2007): Social exclusion and mental health: conceptual and methodological review. *British Journal of Psychiatry*, 191, 477-483.
- De Heer-Wunderink, C., Visser, E., Sytema, S., Wiersma, D. (2012): Social inclusion of people with severe mental illness living in community housing programs. *Psychiatric Services*, 63(11), 1102-1107.
- Department for Work and Pensions (2013): Employment and support allowance: outcomes of work capability assessments Great Britain – new claims. *Department of Work and Pensions Quarterly Official Statistics Bulletin* (22nd January 2013 Ed.).
- Dixon, L. B., Dickerson, F., Bellack, A. S., Bennett, M., Dickinson, D., Goldberg, R. W., Lehman, A., Tenhula, W. N., Calmes, C., Pasillas, R. M., Peer, J., Kreyenbuhl, J. (2010): The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. *Schizophrenia Bulletin*, 36(1), 48-70.
- Evans-Lacko, S., Brohan, E., Mojtabai, R., Thornicroft, G. (2012): Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine*, 42(8), 1741-1752.
- Fakhoury, W. K., Murray, A., Shepherd, G., Priebe, S. (2002): Research in supported housing. *Social Psychiatry and Psychiatric Epidemiology*, 37(7), 301-315.
- Goldman, H. H. (2010): Will health insurance reform in the United States help people with schizophrenia? *Schizophrenia Bulletin*, 36, 893-894.
- Goldman, H. H., Karakus, M., Frey, W., Beronio, K. (2013): Economic grand rounds: financing first-episode psychosis services in the United States. *Psychiatric Services*, 64(6), 506-508.
- Haro, J. M., Novick, D., Bertsch, J., Karagianis, J., Dossenbach, M., Jones, P. B. (2011): Cross-national clinical and functional remission rates: Worldwide Schizophrenia Outpatient Health Outcomes (W-SOHO) study. *The British Journal of Psychiatry*, 199(3), 194-201.
- Harrow, M., Grossman, L. S., Jobe, T. H., Herbener, E. S. (2005): Do patients with schizophrenia ever show periods of recovery? A 15-year multi-follow-up study. *Schizophrenia Bulletin*, 31(3), 723-734.
- Harvey, P. D., Heaton, R. K., Carpenter Jr, W. T., Green, M. F., Gold, J. M., Schoenbaum, M. (2012): Functional impairment in people with schizophrenia: focus on employability and eligibility for disability compensation. *Schizophrenia Research*, 140(1), 1-8.
- Hughes, R., Haywood, M., Finlay, W. (2009): Patients' perceptions of the impact of involuntary inpatient care on self, relationships and recovery. *Journal of Mental Health*, 18(2), 152-160.

- Kleim, B., Vauth, R., Adam, G., Stieglitz, R-D., Hayward, P., Corrigan P. (2008): Perceived stigma predicts low self-efficacy and poor coping in schizophrenia. *Journal of Mental Health*, 17 (5), 482-491.
- Linhorst, M. (2006): *Empowering people with severe mental illness: a practical guide*. Oxford University Press.
- Magallares, A., Perez-Garin, D., Molero, F. (2013): Social stigma and well-being in a sample of schizophrenia patients. *Clinical Schizophrenia & Related Psychoses*, 1-20.
- Mandiberg, J. M. (2012): The failure of social inclusion: an alternative approach through community development. *Psychiatric Services*, 63(5), 458-460.
- Marwaha, S., Johnson, S., Bebbington, P., Stafford, M., Matthias, C., Angermeyer, M. C., Brugha, T., Azorin, J. M., Kilian, R., Hansen, K., Toumi, M. (2007): Rates and correlates of employment in people with schizophrenia in the UK, France and Germany. *The British Journal of Psychiatry*, 191(1), 30-37.
- Nelson, G., Sylvestre, J., Aubry, T., George, L., Trainor, J. (2007): Housing choice and control, housing quality, and control over professional support as contributors to the subjective quality of life and community adaptation of people with severe mental illness. *Administration and Policy in Mental Health and Mental Health Services Research*, 34(2), 89-100.
- Perlick, D. A., Rosenheck, R. A., Clarkin, J. F., Sirey, J. A., Salahi, J., Struening, E. L., Link, B. G. (2001): Stigma as a barrier to recovery: adverse effects of perceived stigma on social adaptation of persons diagnosed with bipolar affective disorder. *Psychiatric Services*, 52(12), 1627-1632.
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M. R., Rahman, A. (2007): No health without mental health. *The Lancet*, 370(9590), 859-877.
- Rosenheck, R., Leslie, D., Keefe, R., McEvoy, J., Swartz, M., Perkins, D., Stroup, S., Hsiao, J. K., Lieberman, J. (2006): Barriers to employment for people with schizophrenia. *American Journal of Psychiatry*, 163(3), 411-417.
- Shepherd, G., Boardman, J., Slade, M. (2008): *Making recovery a reality*. London: Sainsbury Centre for Mental Health.
- Sherwin, J. (2010). Leadership for social inclusion in the lives of people with disabilities. *International Journal of Leadership in Public Services*, 6 supp., 84-93
- Slade, M. (2009) *Personal recovery and mental illness: a guide for mental health professionals*, Cambridge, Cambridge University Press
- Świtaj, P., Anczewska, M., Chrostek, A., Sabariego, C., Cieza, A., Bickenbach, J., Chatterji, S. (2012): Disability and schizophrenia: a systematic review of experienced psychosocial difficulties. *BMC Psychiatry*, 12, 193.
- Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J., Le Boutillier, C. (2011): Social factors and recovery from mental health difficulties: a review of the evidence. *British Journal of Social Work*, 42, 443-460.
- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M. (2009): Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet*, 373(9661), 408-415.
- Warner, R. (2005): Local projects of the world psychiatric association programme to reduce stigma and discrimination. *Psychiatric Services*, 56(5), 570-575.
- Warner, R. (2009): Recovery from schizophrenia and the recovery model. *Current Opinion in Psychiatry*, 22(4), 374-380.

- Yanos, P. T., Roe, D., Markus, K., Lysaker, P. H. (2008): Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services*, 59(12), 1437-1442.
- World Health Organization (2001a): *The International Classification of Functioning, Disability and Health*. Geneva: WHO. <http://www.who.int/research/en/>.
- World Health Organization (2001b): *Mental health, new understanding, new hope*. Geneva: WHO. <http://www.who.int/whr/2001/en/>.
- World Health Organization (2013): *Mental health action plan 2013 – 2020*. Geneva: WHO. http://www.who.int/mental_health/publications/action_plan/en/index.html.

Izabela Nowak
Piotr Świtaj
Marta Anczewska
First Psychiatric Department, Institute of Psychiatry and Neurology
Warsaw, Poland

Katarzyna Charzyńska
Rehabilitation Clinic, Institute of Psychiatry and Neurology
Warsaw, Poland

Corresponding author:
Izabela Nowak, MA
inowak@ipin.edu.pl